

Erin Mahoney

Testimony for Appropriations P.H. (2/16/2016) – SDA

Senator Formica, Senator Osten, Representative Walker and members of the appropriations committee, my name is Erin Mahoney. I am speaking out today in opposition to proposed cuts to the Alzheimer's Statewide Respite Care Program. My mother, Patricia Mahoney, will be turning 64 years old next month, and she is in the later stage of early-onset Alzheimer's Disease. My mother lives with my 65 year old father, Dennis Mahoney, and they reside in South Glastonbury. My parents are second generation Connecticut citizens, have been married for 43 years, and prior to my mother becoming ill, were looking forward to spending their golden years together.

It was this time five years ago when we received the diagnosis of 'mild cognitive impairment' and were told by my mother's neurologist that her brain scans were consistent with early-onset Alzheimer's. This diagnosis was quite the surprise to all of us – we had known there was something wrong with my mother beyond just her most obvious symptoms up to that point (mostly forgetfulness, anxiety, and increased work-related stress), but Alzheimer's was not something we suspected. I did not grow up with the condition in my family, and it was hard to grasp that someone as intelligent, vivacious, creative, and energetic as my young 59 year old mother could have something so horrible. My mother worked as a Recreation Therapy Director with the elderly and disabled throughout her career – if anyone knew the signs of this condition it was her – but even she had a tough time fully accepting the diagnosis. My mother had left her career a few months prior in late 2011, but for a while she was still independent – she could still drive, cook, read, carry on a conversation, and doll herself up like she had always enjoyed doing. In fact, in the early days it was hard to suspect there was anything seriously wrong with her, at least on the surface – it wasn't until you spoke to her in depth and spent time with her that you would pick up that something was not right.

Fast forward five years later, to the present day, and a drastically different picture emerges of my mother. These past five years have been a roller coaster ride of the worst sort for all of us, and has left my father and I on our own to navigate this disease with little roadmap to follow. My mother has lost all ability to care for herself – she can no longer dress herself, bathe herself or tend to any aspect of her hygiene - she is now fully incontinent - she cannot speak coherently, cannot take most simple instruction, and has random crying outbursts and other behavioral symptoms. However, she still has the ability to smile, to hug, to dance, and even, every now and again – to say "I love you" – it's those tender moments of expression and affection that my father and I have come to relish. However, as the disease continues to progress, those moments will

become fewer and far between until they are gone completely - my mother is expected to lose the ability to respond to all environmental stimuli, just as she's expected to lose the ability to walk, move, sit up, feed herself, and swallow.

Last summer, it became very clear that neither myself nor my father were in a position of being able to tend to my mother 24/7 any longer, and the minimal family respite support we had been receiving was no longer adequate, as my mother's symptoms became more severe. My father and I were both extremely stressed and did not know what to do. My father was also experiencing his own health challenges and needed a hip replacement – so at one point I was tending to both of my parents needs' while working in a full time job that required lots of travel (a job that I loved but unfortunately no longer have). Since we could not afford the astronomical costs of out of pocket home care assistance, I found out about the statewide respite care program through my own research. We applied, and then were approved early last fall. With the respite care grant, my mother has been able to attend the adult day care program in East Hartford, going four days a week, four hours a day over the past five months. The 16 hours a week that my mother is at the program has allowed my father to tend to his home, run errands – all of which he can no longer do with my mother, go to his doctor's appointments and attend to his own health needs, and has given him an overall much needed break. It's also given us the peace of mind of knowing my mother is being well-taken care of at this point in the disease. Without this assistance I don't know what we would've done – it came at a time when we desperately it.